Article Release Date: **July 29th, 2014.**

Who: **Hope Through Education (H.T.E)**
What: **Audio/Video monitor for Conner.**
Where: **Temecula, CA**
***When*:** **Event held July 29 th, 2014.**

Hope Through Education (H.T.E.) learned of a local family's child in need and the organization quickly sprang into action to make a difference. You see Conner, still only weeks old, was born with a genetic condition called Cornelia de Lange syndrome (CdLS) in June 2014. CdLS is also sometimes known as Brachman De Lange Syndrome, Bushy Syndrome, or Amsterdam Dwarfism. See detail below for further info about this syndrome.

H.T.E. later learned that the family was in immediate need of a specialized audio/video baby monitor recommended by the San Diego Mary Birch hospital. The cost of such monitor was roughly $270. The family accepted a fifty dollar donation from H.T.E. to assist in this important purchase of the needed equipment. Remainder of the cost would be taken care of by other family members to complete the purchase & arrange for this monitor to be installed promptly at Conner's home in Temecula. Delivery of the H.T.E. funds was completed on Tuesday, July 29th. This will allow for close child monitoring which will include video and auditory surveillance via family cell phone. An important feature for a special needs child no doubt !

"This donation falls right in line with our vision and purpose as a organization assisting kids and families in need" according to Jonathan Hefferlin, H.T.E.'s acting Secretary. Hope Through Education is a Christian based non-profit organization dedicated to uplifting the needy by providing food, clothing, shelter and education. We support orphanages, special homes for the chronically ill & handicapped children, perform various projects for people at risk in Southern California, Mexico & Africa. Mission is to provide education and basic necessities for the betterment of humanity. Vision is to invest in lives with education and sustaining projects for a brighter tomorrow.

Lesa Sobek who accepted & delivered the funds on behalf of the family mentioned " Our family can't thank you and your organization enough for your generous donation to help off-set the cost for a baby monitor for our grandson Conner. Your donation is so appreciated and is a blessing to his parents ". "Helping a group of kids OR an individual child are both equally important and worthy efforts" stated Judy Ward, H.T.E's current Treasurer. Let's pray often for the health and development of Conner & strength for his family as they face challenges most of us will never know.

H.T.E. ~ Vision to Invest in people's lives with education and sustaining projects for a brighter tomorrow
H.T.E. ~ Mission to provide education and basic necessities for the betterment of humanity.
For Hope Through Education website, go to @ **www.hopethroughedu.org.**

Mission accomplished ~ $ 50 donated to local Temecula family for special needs Baby monitor purchase !

Article written by: Paul Wojtkowski, 07/30/14.

END

What is Cornelia de Lange syndrome?

Cornelia de Lange syndrome is a developmental disorder that affects many parts of the body. The features of this disorder vary widely among affected individuals and range from relatively mild to severe.

Cornelia de Lange syndrome is characterized by slow growth before and after birth, intellectual disability that is usually severe to profound, skeletal abnormalities involving the arms and hands, and distinctive facial features. The facial differences include arched eyebrows that often grow together in the middle (synophrys); long eyelashes; low-set ears; small, widely spaced teeth; and a small, upturned nose. Many affected individuals also have behavior problems similar to autism, a developmental condition that affects communication and social interaction.

Additional signs and symptoms of Cornelia de Lange syndrome can include excessive body hair (hypertrichosis), an unusually small head (microcephaly), hearing loss, short stature, and problems with the digestive tract. Some people with this condition are born with an opening in the roof of the mouth called a cleft palate. Seizures, heart defects, eye problems, and skeletal abnormalities also have been reported in people with this condition.

How common is Cornelia de Lange syndrome?

Although the exact incidence is unknown, Cornelia de Lange syndrome likely affects 1 in 10,000 to 30,000 newborns.

What genes are related to Cornelia de Lange syndrome?

Mutations in the *NIPBL*, *SMC1A*, and *SMC3* genes can cause Cornelia de Lange syndrome. *NIPBL* gene mutations have been identified in more than half of all people with this condition; mutations in the other two genes are much less common. The proteins produced from all three genes play important roles in directing development before birth. Within cells, these proteins help regulate the structure and organization of chromosomes and are involved in the repair of damaged DNA. They also regulate the activity of certain genes in the developing limbs, face, and other parts of the body.

Mutations in the *NIPBL*, *SMC1A*, and *SMC3* genes can cause Cornelia de Lange syndrome by disrupting gene regulation during critical stages of early development. Studies suggest that *SMC1A* and *SMC3* gene mutations tend to cause somewhat milder signs and symptoms than those seen with mutations in the *NIPBL* gene.

In about 35 percent of cases, the cause of Cornelia de Lange syndrome is unknown. Researchers are looking for additional changes in the *NIPBL*, *SMC1A*, and *SMC3* genes, as well as mutations in other genes, that may be responsible for this condition.

How do people inherit Cornelia de Lange syndrome?

When Cornelia de Lange syndrome is caused by mutations in the *NIPBL* or *SMC3* gene, this condition is considered to have an autosomal dominant pattern of inheritance. Autosomal dominant inheritance means one copy of the altered gene in each cell is sufficient to cause the disorder. Almost all cases result from new gene mutations and occur in people with no history of the condition in their family.

Cases of Cornelia de Lange syndrome caused by *SMC1A* gene mutations have an X-linked pattern of inheritance. A condition is considered X-linked if the mutated gene that causes the disorder is located on the X chromosome, one of the two sex chromosomes. Studies of X-linked Cornelia de Lange syndrome indicate that one copy of the altered gene in each cell may be sufficient to cause the condition. Unlike most X-linked conditions, in which males are more frequently affected or experience more severe symptoms than females, X-linked Cornelia de Lange syndrome appears to affect males and females similarly. Most cases result from new mutations in the *SMC1A* gene and occur in people with no history of the condition in their family.

END